

RARE DISEASE DAY

2011

BY THE GOVERNOR OF THE STATE OF NORTH CAROLINA

A PROCLAMATION

WHEREAS, according to the National Institutes of Health, there are nearly 7,000 diseases and conditions considered rare (each affecting fewer than 200,000 Americans) in the United States; and

WHEREAS, according to the National Institutes of Health, while each of these diseases may affect small numbers of people, rare diseases as a group affect almost 30 million Americans; and

WHEREAS, many rare diseases are serious and debilitating conditions that have a significant impact on the lives of those affected; and

WHEREAS, while nearly 340 orphan drugs and biologics have been approved for the treatment of rare diseases affecting between 11 and 14 million people, according to the Food and Drug Administration, leaving well over 15 million Americans with rare diseases have no treatment specific to their disease, according to the National Institutes of Health; and

WHEREAS, individuals and families affected by rare diseases often experience problems such as a sense of isolation, difficulty in obtaining an accurate and timely diagnosis, few treatment options, and problems related to accessing or being reimbursed for treatment; and

WHEREAS, some rare diseases, such as "Lou Gehrig's disease" and Huntington's disease, are relatively well known, many others are not known at all by the public, so that patients and their families must bear a large share of the burden, such as raising funds for research; and

WHEREAS, thousands of residents of North Carolina are among those affected by rare diseases, since nearly one in 10 Americans have rare diseases, according to the National Institutes of Health; and

WHEREAS, the National Organization for Rare Disorders (NORD) is organizing a nationwide observance of Rare Disease Day on February 28, 2011, and patients, medical professionals, researchers, government officials, and companies developing treatments for rare diseases are joining together to focus attention on rare diseases as a public health issue on that day;

NOW, THEREFORE, I, BEVERLY EAVES PERDUE, Governor of the State of North Carolina, hereby proclaim February 28, 2011, as "RARE DISEASE DAY" in North Carolina, and commend its observance to all citizens.

BEVERLY EAVES PERDUE

IN WITNESS WHER North Carolina at the Capital in thousand and ten, and of the Independence of United States of American the two hundred and thirty-fifth.